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ABSTRACT

Written in question and answer form, the guide for parents of mentally handicapped children provides information in the areas of health and medical concerns, assessment of the child's mental ability, parent-child-family relationships, education, psychological and psychiatric adjustments of both child and parent, improving communication, and recreation. Also included are aspects of vocational training, legal and social security provisions, community responsibility, agencies and parent organizations, developmental landmarks for normal and Downs Syndrome children, selected reading references, age factors of calorie needs, and a nutrition chart. (RD)

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Counseling Parents of Mentally Retarded Children and Youth

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TABLE OF CONTENTS

Foreword 2

Acknowledgements and Appreciation 3

Introduction 4

Chapter 1 – Health and Medical Information 5

Chapter 2 – Assessment of the Child's Intellectual Ability 8

Chapter 3 – Parent-Child-Family Relationships 11

Chapter 4 – Education 14

Chapter 5 – Psychological and Psychiatric Adjustments of the Retarded Child and Parent 17

Chapter 6 – Improving Communication 20

Chapter 7 – Recreation 22

Chapter 8 – Vocational Training for the Mentally Retarded 24

Chapter 9 – Legal and Social Security Provisions 27

Chapter 10 – Community and its Responsibilities 29

Appendix A – Some Agencies Serving the Retarded and his Family 33

Appendix B – Organizations of Parents of Mentally Retarded Children in Los Angeles County 34

Appendix C – Comparison of Developmental Landmarks for Normal and Downs Syndrome Children 36

Appendix D – Selected Reading References 38

Appendix E – Age Makes a Difference in Calorie Needs 39

Appendix F – A Guide to Good Eating 40

FOREWORD

The Los Angeles County Superintendent of Schools Office, Division of Special Education has been privileged to sponsor and conduct a Title VI Federal Project entitled "Counseling Parents of Mentally Retarded Children and Youth,"* during the 1968-69 school year. A series of ten lectures were presented to each of six groups of parents of mentally retarded children and youth. Each of the lectures covered a different area concerned with mental retardation such as:

Medical and Health

The Community and the Retarded

Intellectual Abilities

Education

Parent, Child, Family Relationships

Psychiatric and Psychological Adjustments of Parent and Child

Vocational Rehabilitation

Recreation

Communication

Legal and Social Security

The lecturers, all active and expert in their specialties presented information to the parent groups and during the latter half of the period (45 minutes) provided an opportunity for questions and answers. Group counselors (Psychologists) present at each meeting assured group continuity and encouraged questions and discussion. At the same time the group counselors noted the kinds of questions asked by parents and recorded some of the answers given by the lecturers. The overall purpose for the series of lectures was to assist parents to increase their knowledge about mental retardation, and to improve their understanding and acceptance of their retarded child. Evaluations conducted at the end of the series showed an overwhelming and enthusiastic parent response with over 95% of the groups attesting to improved and increased understanding of mental retardation, improvement of relations with their child and a strong recommendation to continue the series.

The present monograph has been written to help parents, teachers and school administrators as well as the general public, to acquire a broader knowledge and understanding of mental retardation and to understand the kinds of questions of concern to parents of mentally retarded children and youth. The positive gains resulting to parents attending such meetings may serve to encourage other school districts and organizations to consider implementing such a program.

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Conducting the series of meetings in Los Angeles County has been a rewarding experience in that the group of lecturers obtained were all specialists and outstanding in their fields. It is with grateful appreciation for their contributions to the parent groups that their names are listed below.

EVIS CODA MD, Director, Kennedy Child Study Center, Santa Monica, California

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ELIZABETH WENZ, Nutritionist, Childrens Hospital, Los Angeles

FRANK MASON, District Manager, Social Security Administration, Los Angeles Region

Each of the six parent groups expressed appreciation for the counselor present at the meetings. They provided continuity and an atmosphere conductive to learning. This Office appreciates very much the services of the following group counselors who have helped to make the counseling series a success.

ARTHUR ATTWELL Ed.D., Professor Education, Cal State College, Los Angeles, and Consulting Psychologist to Los Angeles County Schools Office

DAVID BILOVSKY, Ph.D., Professor Educational Psychology, California State College, Los Angeles

JACK SHARE, Ph.D., Chief Psychologist, University Affiliates Project, Children's Hospital, Los Angeles, California: as of September 1969, Assistant Professor of Special Education, UCLA, Los Angeles, California

To conduct a series of meetings of this type requires the services of an individual with much skill in correspondence, tact and above average amount of perseverance. Possessing these to a high degree is Miss Patricia Martinez, secretary at California State College at Los Angeles, California. Her services as secretary to the project are sincerely appreciated.

Directing a project of this nature becomes a rewarding and stimulating task when one has a group

of experts, and an efficient secretary to work with. It has been the good fortune of the project director, Dr. David H. Fils, to have such fine people contributing to the success of the counseling series. At the same time, such a task could not have been accomplished without the encouragement and support of the Los Angeles County Board of Education, the Office of the Los Angeles County Superintendent of Schools, and the Division of Special Education under its Director, Miss Jean Terry Wood.

For permission to reproduce the charts "Age Makes a Difference in Calorie Needs" and "A Guide to Good Eating," the writers are indebted to the National Dairy Council and the Dairy Council of California.

Most grateful appreciation is extended to Dr. Arthur Phelan, Director, Title VI Federal Projects in the California State Department of Education and to members of his staff for their approval and counsel in the operation of the present project.

DAVID H. FILS – Ph.D.
Project Director and Editor

ARTHUR A. ATTWELL, Ed.D.
Group Counselor and Co-Editor

INTRODUCTION

The chapters that follow are not arranged in any priority sequence. The material contained within the chapters is intended to provide the reader with information concerning the various aspects of mental retardation and with a representative sampling of questions of concern to parents of retarded children and youth.

The editors found it difficult to prevent overlapping of some of the content within each chapter. For example, questions of a psychological and educational nature were asked of many of the lecturers regardless of their specialty. Their responses were accordingly noted and appear in a number of the chapters. Perhaps presenting other points of view even if different is a stimulating experience.

Each of the three group counselors took notes on the lectures, the questions asked by parents and answers given by the lecturers. The project director and counselors arranged the material to form the body or structure of the present publication. Though it was primarily intended to reach parents, the information presented will be of value to teachers of the trainable mentally retarded, to school administrators, psychologists, counselors, and welfare agencies working with the retarded, and to colleges and universities as a supplementary reference for courses in mental retardation.

Rewriting and editing of the chapters and arranging the publication in completed form was done by Doctors David H. Fils and Arthur A. Attwell.

The editors will be happy to receive comments and reactions by the reader to the material presented.

Chapter 1

HEALTH AND MEDICAL INFORMATION

Mental retardation is a term which is becoming increasingly more familiar to us, yet one which can be easily misunderstood. Some confuse it with mental illness; others, as a disease in itself. Actually, it can be looked upon as a sympton resulting from a disease, an injury, an obscure failure of development, or even from a prolonged and inadequate opportunity to learn. (As fever is a symptom of an infection or some bodily imbalance, so mental retardation may be a symptom resulting from birth injury, infection, inadequate stimulation in infancy and childhood, biochemical disorders in the body, or chromosome imbalance.) It may well be more helpful to focus less attention on the symptom, and more attention on the condition, itself.

Though most forms of retardation are of a lasting nature, a few preventable forms do exist and respond to medical measures, providing treatment is begun early in infancy. For this reason, a thorough medical evaluation provided by a physician experienced in mental retardation is of utmost importance.

A careful medical history, physical examination, and certain laboratory evaluations are essential. Laboratory procedures vary a great deal from clinic to clinic. In many cases, a routine blood count, urinalysis, urine for phenyketonuria (PKU), electroencephalogram (EEG) or brain wave tests, and skull X-rays are performed. In addition to these tests, it is good practice to perform a tuberculin skin test, urine amino acid study, and an X-ray of the wrist for determination of skeletal (bone) age. Additional specialized tests may be made by the physician when the nature of the child's condition warrants it.

Signs in a new-born infant which may lead a doctor to suspect mental retardation are convulsions, lethargy, spasticity, very poor feeding ability, and poor muscle tone. Other evidence suggesting cerebral damage are hyperactive aimless movements, lack of alertness, and poor sucking ability. The retarded infant is frequently referred to as a "very good baby," because he seldom fusses and sleeps a great deal. Where parents are concerned about reactions and growth of their baby, it may be well to record their observations over a period of time and inform their physician.

Medical treatment should be administered just as for normal children. Certain drugs may have a desirable effect both in calming the hyperactive, and increasing alertness in the very slow moving mentally retarded child.

Nutrition for the mental retardate is important. Dental care and the use of fluoride fortified water is recommended to decrease the need for dental repair. In selected cases, physiotherapy and massage may be of value, when recommended by a physician.

As many parents have concerns that their child may not be getting enough of a certain food, as well as concerns of teaching the youngster adequate self-feeding habits, a discussion of these points will follow.

Fluids such as water, juices, and milk are important. For small infants, the rule is 2¼ oz. for each pound of weight of the infant and for older children and adults, 6 to 8 glasses a day. More is needed on warm days, or during a feverish state.

Calories are a unit of measured energy. Supplying energy is the next important requirement of the body, in addition to air and water. We can estimate how many calories a child needs in this way(1). 1,000 calories at age one and an additional 100 calories for each additional year. This rule needs to be adjusted if a child is more active than usual, or if he is not able to be as active as usual. **To judge if a child is getting adequate calories, we should take into account child's height and rate of growth(2).** A child's appetite is a more accurate guage of his body's needs than is an adults. Unless the youngster is ill, or unable to communicate his needs, appetite can be interpreted as a need for foods.

Protein is the substance our bodies use for growth and replacement of tissues. Such foods as milk, meat, poultry, fish, cheese, eggs, peanut butter, and dried peas and beans are rich in proteins. Finally, vitamins and minerals are important substances as body regulators for they improve the body's use of all foods and maintain certain vital functions. Your physician can advise if your child needs vitamins.

Some retarded children have difficulty in chewing and swallowing. The texture of foods can be modified by chopping or pureeing foods. It is important to offer more advanced forms of foods because development may be retarded, but gradually foods of a more coarse form can be eaten. If textured foods are delayed for a long time, the child becomes resistant to any foods except liquids and pureed foods. Children may tire more quickly from

1. Appendix E, 'Age Makes a Difference in Calorie Needs' Dairy Council of California.
2. Appendix F, **A Guide to Good Eating.** Dairy Council of California, 1968. Supplied free on request.

the process of eating, so food can be offered more often, or in more concentrated form. All foods should supply more food value than merely calories.

A prolonged imbalance of food intake can create a deficiency and the child may be undernourished. Excess fats and candies, or even too much of the basic foods can result in overweight, putting a burden on the body, expecially if there is a physical limitation in movement.

Children may reject solid foods at first, but may accept them more readily when hungry. Solids should be offered just at the lips so the child removes food with his lips and tongue. Self feeding and drinking from a cup or any step toward these goals will mean a feeling of accomplishment for the parent and child. Chewing improves coordination of facial muscles, speech development, and hand to mouth motions of the arm. Sociability at meals is important. Whenever possible, feed the child or allow him to eat while others are eating. The example of other children eating will reinforce the self feeding instruction. It also gives the child a sense of belonging, and accomplishment when he is able to eat at the table with others.

The child can sometimes accept new foods by observing the pleasure others in the family experience while eating. A survey of methods of introducing new foods to children showed that school lunch programs were most influential in introducing new dishes to pupils. Another desirable method has been through nutrition education programs in the schools. These classes can be conducted as a group experience, perhaps including the shopping, preparation, serving, as well as eating the food. Children are more apt to try those foods when they have played a large part in their preparation. Examples have been given of a child, who though apparently unable to chew, watched her parents enjoy a solid food which might be called difficult to eat (pepperoni). As she reached out her hand for some, the parents were surprised to find that the child chewed and swallowed the food, apparently because of their own parents pleasure in eating the food. Some typical questions in this area include the following:

I. Q. **Can disorders of chemical balances in the body be cured?**

A. Yes. There are several conditions in which the body is unable to break down certain foods because of so-called enzyme imbalances. Phenylektonuria (PKU) is a hereditary condition which limits the child's ability to use up, or metabolize certain amino acids (phenylalanine), causing a toxic substance to circulate through the blood, and to damage certain brain cells, thus affecting the child's mental growth. If identified at birth and placed on a special diet (phenylac), the child can develop normally.

Another condition, galactosemia, the inability of the infant to metabolize or use up galactose (in both cow's milk and mother's milk), can result in mental retardation if the child is not placed on a galactose-free diet. Sucrose or dextrose may be substituted. The above two conditions are diagnosable soon after birth. In California, all newborn must be tested for such heritable conditions.

II. Q. **What is the percentage risk of having a child with Down's Syndrome? (Mongolism).**

A. According to recent studies, the following data are provided:

Age of mother at time of delivery.	Chances of having a child with Down's Syndrome.
15-19 years	1 in 1800
20-24 years	1 in 1600
25-29 years	1 in 880
30-34 years	1 in 500
35-39 years	1 in 200
40 and over	1 in 50

Ideally, it would be well if all children with Downs Syndrome could have a chromosome analysis. This is not practical at present, because of the expense and the relatively few centers available for such an analysis. The fees vary from $50 to $200. In some cases, special studies may be obtained at no cost when part of a research study. The time for a complete analysis may vary from one week to several months, depending on the extensiveness of the testing and the waiting list.

III. Q. **What causes Downs Syndrome (Mongolism)?**

A. The cause has been linked to an extra chromosome in the so-called G group. This extra (47th) chromosome usually occurs at the time of fertilization. At this time, the exact mechanics involved in causing this extra chromosome are not known. It is known, however, that approximately 95% of all cases of Downs Syndrome seem to be caused by non-hereditary factors. To date, 14 varying chromosomal types have been identified in children with this disorder. If the mother is under 25 years of age, a chromosome count would be warranted, as younger mothers of children with Downs Syndrome have a greater tendency to be a "balanced translocation" carrier. If the mother is over 40, there is a greater likelihood that the cause, rather than a translocation problem is related to her age and the so-called exhausted fertility. The majority of births of children

with Downs Syndrome are to mothers in the more mature age group. Additional research data on comparing the development of normal with Downs Syndrome children appear in Appendix C.

IV. Q. **Where can one go for further information on mental retardation regarding diagnosis, treatment, training, counseling, etc?**

A. First, check with your family doctor. If he is unable to provide you with such information, it is advisable to contact one of the Regional Centers for the Mentally Retarded. Such centers are located in the Children's Hospital in Los Angeles, San Diego Children's Hospital, also through the Retarded Children's Associations in San Francisco, Fresno, Sacramento, and other larger cities. Additional centers are available in the Los Angeles area. These include the Kennedy Child Study Center, USC Medical Center, White Memorial Hospital, Exceptional Childrens' Foundation, and the Van Nuys Health Center. The UCLA Neuro Psychiatric Institute also provides diagnosis, prescriptive, and training services. A telephone call and appointment at one of these centers will bring the parents fairly complete services for the child and his family, and thus prevent the tendency on the part of the parents to go on prolonged diagnostic and therapeutic "shopping tours."

V. Q. **Is sterilization of retarded children recommended?**

A. Mandatory sterilization is not generally advisable since most cases of retardation are not hereditary. In fact, there are many cases cited in the literature in which retarded mothers have given birth to normal children. A thorough examination of the child and his family history, plus medical and parent conferences should precede any intent to have the child sterilized. Colorado and Maryland are the only two states at present having legalized abortion laws for defective embryo.

VI. Q. **Can petit mal epilepsy affect a child's IQ score?**

A. Most doctors believe not necessarily so. In many cases a patient may have an inherited tendency that makes it easier to develop seizures but this is only a tendency and there are persons who do not have epilepsy who have inherited such traits. Epilepsy generally does not get worse with age. Sometimes the seizures may lessen in frequency and intensity as the person grows older.

About one percent of our population have some form of epilepsy. More than 80% of the cases can be at least fully or partially controlled with medication prescribed by a physician.

VIII. Q. **Doctors sometime mention the word EEG in a physical examination. What does this mean?**

A. An EEG is a brain wave test, called electroencephalogram by doctors. It is a machine that records the electrical waves that pass through one's brain to determine if there is any damage such as epilepsy, tumors or other growths. It is a harmless and non painful procedure that helps the doctor in making a diagnosis, and prescribing correctly whenever possible.

IX. Q. **What is the XYY Syndrome?**

A. Normally, the father carries an X and a Y chromosome, believed to determine the sex of the offspring. In the cell division at fertilization, one of these chromosomes is united with that of the mother, who produces only the X chromosome. The Y chromosome, being dominant, produces a boy. If the father's X chromosome is fertilized, the father's and mother's combined X-X chromosomes produce a girl. The XYY Syndrome refers to the addition of an extra male chromosome, which some researchers suggest causes greater male aggressiveness. Research is still going on in this area, and the findings are only suggestive. The relationship of this condition to mental retardation does not seem clear at this time.

X. Q. **What can be done to prevent mental retardation?**

A. Some things can be done to prevent or lessen the incidence of mental retardation in our population.

For the Mother

1. Adequate pre natal care
   a) Regular medical checkups
   b) Balanced diet
   c) Avoidance of infections, injuries, diseases especially during first three months of pregnancy
   d) Avoidance of excessive smoking and heavy physical activity
   e) Medication only on physicians advice
   f) Medical laboratory exams as indicated, eg (blood compatibility).

For the Child

1. Testing at birth for heritable diseases and applying corrective measures
2. Proper and adequate diet
3. Required immunizations
4. Adequate stimulation
5. Immediate care and treatment of childhood diseases, physical-head injuries
6. Love, attention, affection

Chapter 2

ASSESSMENT OF THE CHILD'S INTELLECTURAL ABILITY

In order to be enrolled in classes for the Trainable Mentally Retarded in California, a pupil must meet the following seven criteria: 1) Be able to hear spoken connected language, 2) Be ambulatory to the extent that no undue risk to himself or a hazard to others is involved in his daily work and play activities, 3) Be trained in toilet habits so that he has control over his body functions to the extent that it is feasible to keep him in school, 4) Be able to communicate to the extent that he is able to make his wants known and to understand and follow simple directions, 5) Be developed to the extent that his social behavor does not endanger himself and the physical well-being of other members of the group, 6) Be emotionally stable to the extent that group stimulation will not intensify his problem unduly, 7) Be incligible for admission to special classes for the educable (mildly) retarded.

Interestingly, the IQ score, as such, is not mentioned in the California State Education Code, though a school psychologist must have administered intelligence tests to a youngster, and must state that the child is mentally retarded and that he cannot profit from classes for the educable retarded. Though the IQ score, itself, is not a sole criterion, the test scores of these youngsters (trainable) generally fall somewhere between 25 and 55. The general level of the child's functioning at home, neighborhood etc. is additionally considered. The school is constantly on the alert for behavoral or intellectual changes which might affect the child's optimal placement. Recommendations for placement changes are based in part on the assessment of his level of intellectual functioning and teachers' recommendations. Following are some commonly asked questions in this area:

I. Q. What is intelligence?

A. Generally, intelligence is considered as the ability to do things -- to perform at appropriate age levels. More specifically, intelligence is considered as behavior in many domains, or areas. There are perhaps any number of actual separate areas of functioning (intelligence); in fact, Professor J. P. Guilford has already identified more than 100 possible areas. For general purposes, however, we can consider intelligence as including four large areas of behavior:

(1) **Cognitive Competence.** This involves the primary intellectual abilities considered necessary for academic progress. Areas of ability such as language, number concepts, reasoning, immediate and delayed memory, and recall would fall into this category.

(2) **Social Competence.** Follow-up studies of mental retardates has indicated that this particular area of intelligence is more important to the successful adjustment of the individual than the cognitive area. Social competence refers to the degree to which one can adjust to others -- to their peers and to adults within their society. This area is concerned, for example, with how well the youngster (or young adult) gets along with his boss, with the workers, whether he is able to be on time, to finish a task, to accept suggestions, to make a change in tasks or schedule, and so on. Intellectual factors may complicate the problems of the retarded but personality factors determine his fate!

(3) **Emotional Competence.** This involves the degree of total personality balance; that is, the control of one's feelings, anger, hate, love, his frustration tolerance, etc. Both the retarded as well as the normal child or adult make frequent use of defense mechanisms (to maintain feelings of self worth) but perhaps the individual with a lower level of emotional stability will rely more on such mechanisms as lying, anger, avoidance, blaming others, fantasy, etc.

(4) **Perceptual - Motor Abilities.** This category indicates the degree to which an individual can function developmentally, or how well "wired" he is. It involves his ability in hand-eye coordination, eye-foot coordination, distance perception, figure-ground relationships or space relationships and paper-pencil tasks. Difficulties in performance in these areas arise some times from brain damage or neurological handicaps. Many schools now have specialized educational methods to overcome some of the above difficulties of children.

II. Q. Is one area of intelligence more important than others?

A. Perhaps the area of social competence has more implications for success in adult life, as was discussed in the previous question. However, attempts to develop one area independently from the

others have not been found profitable. A recent emphasis, for example, has been to focus on perceptual motor development as being of major importance, and have involved the creeping-crawling movement exercises as a means of stimulating total growth in the retarded child. A recent report, published by the National Mental Health Institute of Washington, D.C., and appearing in the Nov., 1967, issue of the American Medical Association Journal reports no evidence to prove the usefulness of the perceptual motor heirarchy method, as advanced by the Dolman-Delacato School. There may be risks to parents who may become over emotionally involved or feel some guilt if they do not at least try this method, regardless of cost. Here again a parent may wish to obtain counsel from a child guidance clinic, a children's hospital or their family physician regarding the various therapies available.

III. Q. **How do we account, then, for the numerous cases in which a child did show improvement when given patterned exercises?**

A. There is always a possibility that this type of improvement might have resulted from physiotherapy or occupational therapy, or even natural growth. We would have to know more about the growth patterns of the given individual and how the therapy methods were used. There is also the parent with a "self-fulfillment prophesy" type of attitude, in which one who so eagerly and sincerely desires to see improvement in her child tends to "see" it, and to overestimate the improvement.

IV. Q. **Just what does the term "psychological testing" imply?**

A. There are many forms of psychological tests, dating back to the turn of the century when Simon and Binet first developed a test of ability for children in France. When we speak of psychological tests for our retarded children, however, we generally have reference to intelligence testing. Of these tests, which are routinely given to the children in special classes, the Stanford Binet and the Wechsler Intelligence Scale for Children are probably the most frequently and widely used. These tests which usually take from 30 to 50 minutes to administer by a psychometrist or psychologist, give a general level of mental functioning of the child. There are several other types of intelligence tests which might be used, depending on the nature of the child's handicap, and his level of visual, verbal or motor ability.

Since a test battery is routinely given about every two to three years (and more frequently, if indicated), the tests give the examiner an indication of the rate of the child's intellectual growth, and clues as to his various strengths or weaknesses. This can help in identifying the areas in which the child can be best expected to learn, and the means by which the child's weaknesses can be improved. The tests may serve as one basis for establishing an "individualized curriculum" at school. The school psychologist works with the child's teacher in effective programming of the child's activities. There are also various projective (personality) tests, which are less commonly used with the retarded child, but which may help to pinpoint the areas of difficulty in the child with emotional problems. The real test of a classification system should be based on how well it serves the person being classified. If it merely labels him or prevents him from receiving services it is a questionable scheme.

The test results do present a sample profile of the child's abilities and provides the examiner with data suggesting the various strengths and weaknesses. The examiner can then present and interpret these to the child's teacher and parent. Testing is more useful when it is prescriptive, rather than for purposes of classification. This means the teacher learns of the child's specific abilities and plans a program around these abilities.

Test makers continue to study and experiment with newer methods, techniques and instruments designed to better measure a child's abilities.

V. Q. **Should the parent be informed of the results of the tests?**

A. The school psychologist or principal is usually happy to interpret the test results to the parent. The parent has every right to request and receive any information regarding his child's profile of intellectual strengths and weaknesses, just as the teacher has an obligation to use this information in planning for the child's training activities. There is grave danger of misinterpretation, however, when IQ scores are freely distributed without proper explanation. (1) The various tests measure separate aspects of ability; verbal, auditory, or visual discrimination, motor performance, etc.; therefore, a descripiton of what might seem to be a total pattern

of abilities by a single IQ score on a given test, would be most inadequate in trying to learn about the child's specific assets. (2) Children, themselves, change. Medical, maturational, emotional, or environmental factors affect a child, and may thus affect his performance at a given time. (3) An "IQ" test is really only a sampling of a child's behavior during a period of less than an hour. One cannot and should not predict the child's total future behavior on any one particular score.

Chapter 3

PARENT-CHILD-FAMILY RELATIONSHIPS

The individual human being develops as a total personality as a result of the relationships he has had with those in his immediate environment and as a result of the way in which he perceives and interprets these relationships. It is in the home setting that many problems may develop; however, this is also the setting in which most problems can be resolved or prevented.

A chain of events occurs by which all of the members of the retarded child's family are influenced in varying degrees by his presence. The manner in which the family responds to the child at the very onset of his birth, or their discovery of his condition, becomes significant to the child as he begins to relate with and see himself within the family constellation. If he is loved, cared for, and accepted, he sees himself in one way. On the other hand, should he be rejected, left to himself, indulged in, or overly protected, he will begin to develop a different concept or feeling about himself.

Experience has shown that retarded children have difficulty in developing self-help skills; dressing grooming, feeding, toilet training, etc. Parents of young children will do well to make experiences which undoubtedly involve a degree of frustration to both parents and child, as pleasant and positive as possible.

Because of the kinds of things we value in our culture, we tend to place more emphasis on success and to shy away from failure. As a result, we have been, perhaps subconsciously more proud of our gifted and defensive about our dull and retarded. As families continue to gain information and understanding about mental retardation, however, the need for this defensive behavior gradually lessens. We now realize, for example, that the retarded child is far more **like** the normal child than **unlike** him. Very often the difference is quantitative rather than qualitative. The feelings, moods, desires, etc., of the retarded are similar to those of the normal child. The difference is in the mental age or level of maturing; thus, the same "rules" about child-rearing and effective sibling relationships apply, whether there is a retarded child in the family or not.

Often, however, parents find it more difficult to accept a delay in the growth and development of their retarded child than in their normal child. The parents more readily understands and accepts normal developmental characteristics in his child at the usual age than in his retarded child at a later, delayed age.

Generally, it is more common for parents to over-estimate than to under-estimate their child's abilities. Parents eagerly watch for signs of progress in their young retarded child, and may attach more significance to acts of learning than is appropriate. There is a tendency, for example, to be overimpressed with things the child has retained, and to state that the child has a "memory like an elephant." One of the important adjustments a family must make to its retarded child is to recognize and accept that the child's social, emotional and often physical growth may be more gradual and uneven than in his normal brothers and sisters.

Related to the parents natural desire to see their child progress is the tendency to do things for the child that he should learn to do for himself, in the hope that this will help him to learn to do the task. An important need of the youngsters is the development of feelings of independence. Once the infant's need for security has been provided for through the parents' care and affection, he must soon learn that mother and father will not do **everything** for him. When a child is ready to eat by himself, for example, he should not be fed. When he is ready to assume responsibility for performing tasks, he should perform them. To withhold these experiences from a child will thwart his normal growth, and will perpetuate his feelings of inadequacy and dependence. Actually, the weaning away process, towards independent behavior starts at birth and increases for the remainder of his life. Following are some of the questions most commonly asked regarding family relationships:

I. Q. **Will my child's emotional growth be affected if the home atmosphere is not a good one?**

A. It is not reasonable to assume that merely because a child is retarded, his emotional development will not be affected by his home situation. In this respect, he is not unlike his normal brothers and sisters. A warm, accepting home is generally the best security for the normal total development of a child of any level. Like normal children, the retarded can withstand normal parental or family differences; therefore the natural resilience of the child will usually overcome most day-to-day crises which may occur. Chronic, ongoing, unresolved crises may

be too overwhelming, for the child and professional help may be indicated.

II. Q. **Can emotional problems affect the child's health or school work?**

A. Yes. Prolonged unresolved family tensions can result in physical and emotional problems in the young retardate, as well as with all other members of the family. The retarded child is not shielded from such problems because of retardation, any more than are his parents or siblings. Upset stomachs, fainting spells, speech difficulties, high blood pressure, skin rash, etc., are but a few of the common symptoms, even though a medical examination may show no organic causes.

School work is directly affected by emotional problems, in fact, inadequate social and emotional development has been found to be the greatest single cause of failure to succeed in school as well as in a sheltered workshop.

III. Q. **My child will not let me leave him without crying. What will happen when he goes to school next fall?**

A. Children below the age of three and four years need a close contact with a parent, preferably the mother. There is a closeness which takes place within a home, and which provides a basis for future stable development. This is especially important from early infancy to age two and one half or three. By the age of three to four, however, the parent must gradually prepare the child for eventual separation by being gone for brief periods, perhaps two or three mornings a week. The sudden "shock" of separation can be avoided by the use of the gradual weaning away method suggested above. The shock to the child, however, is generally far less than the parent believes and is sometimes exaggerated by the child to reassure and continue parent protection. The occasional "trauma," or "separation anxiety" is found when some parents of non-retarded children first take their children to kindergarten.

IV. Q. **Should the retarded child be punished?**

A. The fact that parents ask this question suggests that they may have some misgivings about punishing a retarded child. Generally, whether the parent might be called "strict" or "lax" is not as important as the relationship with the child. If parents punish their children, the method should be consistent with all their children. The question of the type of discipline, however, should be given consideration. Punishment should not mean abuse. Discipline should not be to hurt, but to teach. Punishment is merely a means through which we teach and hope to change the child's behavior for the better. A parent too frequently becomes emotionally involved in administering the punishment, sometimes providing a "floor show" for the child, and perhaps for the entire family. Sometimes the child's tantrum or destructive behavior provides a defense for the parents' own feelings about the child and thus provide an object on which the parent could project her feelings of anger.

If the stress is on the positive behavior and proper reinforcement used for the desired behavior, rather than on the punishment for the negative behavior, the desired result is far more easily obtained. The parent who administers punishment for misbehavior might ask himself, "has this really worked so far, or is the child still performing the acts for which he was punished?" Generally, the spanking or lecturing parent is merely putting out bonfires, rather than establishing a basis for learning and improved behavior in the child.

The child who frequently uses inappropriate behavior is usually evidencing a need for expression. The goal of the parent should be to direct the behavior into desirable, appropriate channels. In this respect, operant conditioning (rewarding, or reinforcing desired behavior when it occurs; not reinforcing or ignoring poor behavior) has been found most profitable. Too often the child sees punishment as a reinforcement of his behavior. Even a spanking can become a means of a child manipulating a parent, rather than a deterrent of behavior.

VI. Q. **When I leave my child with his grandparents, his behavior becomes worse. How can I keep them from spoiling him when he is there?**

A. Occasional overprotecting or "spoiling" by grandparents of the retarded can be merely an exposure to another form of behavior. This does not damage the child; rather, it broadens him. The issue is not in the act, it is in the child's reaction. He quickly learns that he must resume his former behavior when he returns home.

Children often resort to special means to attract attention and obtain favors from relatives, especially grandparents, who may find it easier, even rewarding, to accommodate the youngster. For prolonged or frequent visits, the parent may wish to remind the relatives of the type of behavior usually expected of the youngster at home.

VII. Q. **My normal teen-ager feels embarrassed about bringing her school friends home because of our retarded child. What should I do?**

A. Teen-age embarrassment regarding siblings is not limited to retardation, but is a normal developmental attitude. When the teenager invites friends to her house, the normal brothers and sisters should be expected to leave their older sister and her friends alone. Why, then, should not the retarded sibling have to do the same thing? Adolescents enjoy and need privacy when they entertain visitors.

There are occasions, however, in which the problem goes deeper, and a change of attitude is needed. Perhaps there is a lack of understanding on the part of the normal teenager, who may need to simply be told that each of us has some sort of defect, and that some of us merely have them to a greater degree than others. Parents have often indulged the retardate to the extent that he feels he should invade every social situation. Also, some parents might not have shared the family responsibility of the care of the young retardate with the teenager. Often, the teenager who has for years shared in this responsibility has a far different attitude than the one who has watched her parents do all the caring for the retardate. The teenager's attitude and level of understanding are easily influenced by the parents' treatment of the young retardate.

VIII. Q. **Should we take our retarded youngster with us when we go to a restaurant, theatre, etc?**

A. It is appropriate to take the retarded child on any family outing on which it would be proper to take our other children. Seeing the retarded in public places is no longer a novelty, and should in no way prove an embarrassment to any party.

IX. Q. **How much responsibility can I give my normal children for the care of our retarded child?**

A. The parent knows the type of behavior of the retarded child, and can generally be the best judge of whether the normal child, regardless of age, is capable of caring for his retarded sibling. Assuming responsibility for the occasional care of a retarded child is a healthy attribute, so long as the assignment is reasonable. If the parents are not in a position to judge, perhaps the retarded child's teacher or counselor can be of assistance.

Chapter 4

EDUCATION

A resource which should be available in all communities for all children is the public school. The state, through the local school district and county schools office is now moving in the direction of providing educational opportunities for all children regardless of their limitations, either of nature or nurture. At the present time programs for the retarded in the public schools divide the retarded into three educational groups, the educable, the trainable, and the sub-trainable. In those communities where public school programs for the retarded are either not provided or are provided in inadequate numbers, parent groups have set up classes to provide educational experiences for their children.

The sooner the child is prepared for school entrance the better. The parents must also be prepared. They must be prepared to release part of the care of their retarded child to a stranger. The parents must be able to "let go" of their child for a portion of the day, and the parents must recognize and accept the condition of their child in a frank manner. The entry of the retarded child into the community presents problems and challenges for the parent. The parent is now faced with a new kind of appraisal and comparison of their child. Previous thoughts and feelings about their retarded child may now be subject to reappraisal.

The techniques used in teaching the retarded are very much like the techniques used in teaching the normal. The experiences and the exposures will take longer, are presented at a later age, and will use more movement and action. Wherever possible, the retarded should be given an opportunity to act or perform what is to be learned. This may be in the form of telling a story, obeying verbal commands, or recreating a scene. It is especially important in his relations with others in his class. Interaction with others should be encouraged. The school educational setting presents excellent opportunities for this activity. The retarded child, because of past inadequacies and failures to handle day-to-day happenings frequently responds by isolating himself. The classroom is very important as a modifier of isolation and loneliness.

Such a setting should offer an opportunity for the retarded person to establish a belief in himself and a recognition of his worth. All of us have the basic need to be considered competent. The very act of going to school allows the retarded to develop a "mask of competency" which is so very important in the development of a feeling of achievement.

Education of the retarded, of course, does not stop when he reaches 18. If anything, because of their retardation, age 18 and beyond may very well be the most productive educational period for them in terms of productivity and personal growth. Unfortunately, the mandated program for the trainable in California stops at 18. Some public schools do provide classes on a permissive basis to age 21. Continuation of education for the older retarded is at the present time provided in workshops or adult education programs. These programs are very limited in number as well as in geographical distribution. The need for their expansion is recognized.

Some questions parents ask about the education of retarded are:

I. **Q. My son is in a trainable class. Will they teach him reading, writing and arithmetic?**

A. The child's education should be adapted to his capability as well as to his needs. If he is able to benefit by teaching him the three "R's" then he will be taught them. The fact that he is in a "trainable" class rather than in an "educable" class will not stop a teacher from teaching reading to a retarded child if he shows this capacity. However, it must be understood the amount of effort and the resulting frustration by doing so, in some instances, may serve to aggravate the retarded's feelings of failure and lack of achievement.

II. Q. **My son is in a trainable class. Will he ever be able to graduate to an educable class?**

A. In both types of classes the retarded is taught that which is most appropriate in terms of his level of development and activities needed to function in a community. However, the retarded in the school is under continuous evaluation and if it is felt that he can best be served in a program other than the one he is in then he can be shifted to the more appropriate program. This question also appears to be asking if the IQ of a retarded can improve so that a shift of program is merited. As a rule the intelligence as determined by tests will not vary a great deal with repeated administration of tests. This is not the same as saying that the behavior of the retarded child does not become more intelligent or adaptive. Although the test score of

the retarded may not change, to any great degree, the competency of the retarded through training in self help activities, communication, personal-social areas, physical development, as well as economic or vocational usefulness may be greatly enhanced.

III. Q. **My child is five years of age and when I brought him to school in order to enroll him, I was told to take him home and wait a little while and come back next year when he may be more ready for school.**

A. The mandated program in California for the trainable retarded is for those age 6 to 18 years. However school districts may enroll the retarded at five on a permissive basis. As a rule, maturity or readiness is enhanced through stimulation provided by exposures to learning activities. Because of this, it is suggested that if the retarded is not at the moment eligible for public school, other types of learning experiences, such as those provided by parent groups, should be sought out. If no program for your child is available then the parent should provide experiences of a nursery school nature for him. He should be talked to, read to, engaged in motor activities, etc.

IV. Q. **My child is fearful of new situations and is reluctant to try anything without a lot of pushing.**

A. The retarded usually has had a lot of experience in failing or not achieving. The retarded has a fundamental need to achieve. We must understand his fears of not achieving are real. We should not shame the retarded because of these fears. We can arrange experiences so that achievement is assured. Any requested task should be examined as to whether or not it is a reasonable request. Is the expectation in keeping with the child's demonstrated ability? In other words, can your child do it? Perhaps you can do the task up to the last step and ask your child to complete it thus assuring completion as well as achievement. As an example, you may tie his shoe lace but ask him to draw it tight or you may lace his shoes and allow him to lace the last hole. On subsequent trials you ask him to accomplish additional steps of the task. The retarded also has fears and anxieties which come out of his awareness of his dependence. Because of this, he may have fears and anxieties of being left without a protector. Your presence and your concern for him must be constantly restated and reaffirmed in this instance.

V. Q. **I have been told that my 14 year old has the mind of a seven year old. Does that mean that he is the same as his seven year old brother?**

A. No, it does not mean that at all. He is not the same as a seven year old. He may be able to accomplish no more than a seven year old in such things as reading or arithmetic but he is fourteen years of age when it comes to feelings, emotions, and needs. He hurts and has joys more like a 14 year old than a seven year old. It is just not correct to think of him as a seven year old. His physical development is probably closer to the 14 year old than the seven year old. It is better to think of him as a retarded 14 year old.

VI. Q. **My youngster won't make her bed but will help me make up mine.**

A. In this case we can assume that the child is capable of performing the task. In any examination of tasks we must be able to answer the question, "Why doesn't she do the task asked of her?" Or, "Why should she do the task?" There is usually a "pay off" in our performance of tasks. We have to try to see what are the gains which go along with the execution of a task. The girl who helps her mother make her bed receives companionship, communication, affection, as well as immediate praise for her help. None of these things exist when she makes her own bed by herself. The objective then becomes one of providing similar "pay off's" for the task you want her to perform by herself.

VII. Q. **Will it help my child if I come to school more frequently to see how he is doing?**

A. Teachers are encouraged by the interest parents show in the development of their children. A close cooperation between parent and teacher usually is helpful in furthering the progress of the child. The teacher generally will advise the parent when a conference is desirable. Many schools set a policy of having one or two conferences per year and additional ones when indicated. Sometimes an over-concerned and over-solicitous parent may work to the disadvantage of the child by frequent visits to his class.

Such practice would tend to perpetuate dependency behavior in the child, and also cause an unwelcome interruption in the daily program. Where this excessive concern is present, the parent may be advised to confer with the teacher, principal or school psychologist.

VIII. Q. **When does a parent institutionalize a child?**

A. The large majority of trainable level children tend to remain at home and within the community. Research shows clearly, children in state hospitals for the retarded generally develop considerably less than when living at home. A parent may consider hospitalization when her health (physical or mental) is impaired to the extent that she is unable to care for her retarded child, and financial status does not permit help in the home; when the child requires 24 hour medical care and supervision; when the retarded child or youth commits serious delinquencies or crimes and prognosis for improvement is poor.

When a question of hospitalization of the child is considered, the parents will seek professional counsel and then decide for themselves.

IX. Q. **Do you have any suggestions to help me in toilet training my child?**

A. Dr. Molly Gorelick of the Exceptional Children's Foundation in Los Angeles suggests the following procedure in helping a parent to toilet train her child:

1) Be prepared to devote time and patience to teach your child one skill at a time by a series of small steps.
2) Provide for a great deal of practice for your child.
3) Make directions as simple and as clear cut as possible.
4) **Reward each step of the desired behavior as it is completed.**
5) Use the same setting and equipment for your child each time so that he will understand what you want him to do.
   a. Toilet seat in the bathroom.
   b. Training pants; if slacks are worn be sure they have elastic waist bands so they can be taken off and put on easily.
   c. Be prepared to let him sit on the seat no longer than five minutes, then take him off calmly and gently.
   d. Keep a chart of the times he voids and has a movement, for one week or more.

Chapter 5

PSYCHOLOGICAL AND PSYCHIATRIC ADJUSTMENTS OF THE RETARDED CHILD AND PARENT

Parents of retarded children are not different from parents of non-retarded children. The problems concerning their retarded child are not unique, but are similar to problems faced by parents of non-retarded children. What makes the problems unique in each instance is the attitude of the parent to the problem presented. Actually, parents of retarded children do not want to be looked upon as different or treated differently from other parents. The adequacy of the adjustment to having a retarded child will depend in part on the kind of person the parent was prior to the birth of the baby. A tense, high strung, unstable mother or father will be even more so at the birth of a retarded child. The infant and later, the child, will absorb the feelings and attitudes (spoken and unspoken) of his parents and incorporate them into his own emotional, social and intellectual development. Many parents look upon their newborn as an extension of themselves and psychologically endow their child with their own emotional makeup, and so they see themselves reflected in their child. At the same time perhaps, the child is weaving his own emotional structure with its own emotional threads as well as with those of his parents. Extremes of this type of emotional development lead to a severe blocking of the child's own emotional growth, resulting in management and relationship problems, difficulties in learning and perpetuating dependency behavior. Some parents may also become unhappy, resentful of their retarded child for when they look upon their child, they see themselves reflected as inadequate, incapable of having a normal child.

Most parents of retarded children achieve a reasonable balance in their emotional acceptance of their child and of themselves. Where difficulties arise in this respect, it may be well for parents to seek professional counsel. Actually, parents of retarded children may be helped in their psychological adjustments to their child by seeking such counsel at various critical stages in the growth and development of their child (birth, pre-school and school periods, and after school). A reasonable mature attitude in the parents' management of the child, helps to assure an optimum total growth of the child, barring other organic factors.

Parents have every right to feel confused, concerned, and anxious as well as develop guilt feelings in giving birth to a retarded child. It is difficult to conceive of any parent who (during her pregnancy) is making psychological adjustments to her giving birth to a retarded child. Certainly all the emotional investments of the parents are geared to anticipating a birth of their own image in a boy or girl.

Perhaps for this reason among others, ventilation of parents' feelings in a therapeutic setting is essential at the time of birth of the child or very soon after. The newborn retarded child perhaps from the moment of birth, begins to experience a certain disenchantment with the world about him. His parents, anxious to refute the diagnosis, exposes him to extended diagnostic evaluations, then hopeful of overcoming the condition, expose him to therapeutic procedures. One would feel, the child is wondering with his own primitive sensory equipment – "Why all this fuss?" Further, the child sees the look of mixed feelings in his mothers eyes, questioning, unbelieving, confused, half pity, half sorrow, half joy. He may feel a certain uncomfortableness and lack of warmth when he is held in his mother's arms, or when he is picked up by his father, brother or sister. He may sense that mother is not talking to him much, saying the cute, precious things usually said by mother to child. "Why is mother not looking at me to capture my smile, my wiggly funny movements and then express her joy to me and relate them to our family?" "What can mother and father be saying to each other in such loud voices and mad looking faces? I can hear them from my crib and I kind of feel it is about me – perhaps they are trying to decide who was to blame for my condition. Funny, that Mom and Dad don't invite other people to come and look at me. Something must be wrong even though I am trying my best to smile and act cute and warble."

"I did start late in doing the things most babies do in growing up and I felt very unhappy to see mother trying so hard to help me walk and to go "potty" by myself. Mother keeps taking me to the doctor for shots, and pills and pictures. Am I really so sick? Sometimes I see the doctor shaking his head. Does it mean I can never be cured of whatever I have?"

"I wish Mother would stop worrying about me and leave me alone to do the things for myself. I know she thinks I need help, but I don't think so, at least for doing certain things."

And so the retarded child grows, and continues to build up along the years an image of himself of not being like others, not able to do things that his brothers and sisters do, of being a source of concern, and unhappiness, to his parents. Sometimes his image of himself is brightened, uplifted, when his parents really understand him and accept him for himself and give him things to do that he can achieve by himself and feel the glowing satisfaction of accomplishment. The child then really begins to grow, often beyond the expectations of parents and teachers, once this spark of success is nurtured by opportunities for more success.

Cutting the "dependency" chord from his mother releases a good deal of the child's own natural energies and desires to achieve and emancipate himself. Perpetuating the dependency behavior of the child activates the self-fulfillment prophecy: "I shall be what you think and expect me to be and nothing more."

Fortunately increased independent behavior on the part of the child and adolescent is being encouraged in the special classes, after school activities, camping, teenage clubs etc.

Recognizing the importance of knowledge or information about mental retardation as a step to understanding and increased acceptance of the child, the following questions asked by parents, and answered by the lecturers in the series, are presented.

I. Q. **Do oversensitive parents make for oversensitive children?**

A. Yes. It seems to work this way. After all, children are an extension of ourselves.

II. Q. **Is it okay to use threats on a retarded child?**

A. A lot of threats soon become meaningless as there is no reinforcement. The child may be sensitive and easily frightened causing him to withdraw within himself through threats. It is not the best approach in discipline yet it may be used at times.

III. Q. **What is autism and what can cause it?**

A. It is a type of behavior in the child marked by withdrawal, apathy and lack of response to his environment. Many think it may be related to imbalances in body chemistry, others to severe chronic emotional disturbances. We are still not sure what causes it. There is at present, a great deal of research being done on this disorder. A safer probability may be that the cause or causes may be found in the relationship of bodily chemical imbalance(s) to the nature of the environment in which the child is developing. When parents observe a marked change in the infant or child's ability to relate to others, it may be wise to consult your family doctor who in turn may refer you to a child guidance clinic.

IV. Q. **Can a retarded child become mentally ill?**

A. Yes, almost all children and adults can become mentally ill if exposed long enough and severe enough to emotionally disturbing situations.

V. Q. **My girl is 13 years old and she is already in puberty. She seems to like boys very much and I am concerned. What can I do?**

A. If she didn't like boys, you would be more concerned. No one can give you assurance with any girl, normal or retarded that she will not get into trouble. Do not overprotect her, but take the normal precautions as you would with any girl. The oncoming of puberty is often more of a problem to the parents.

VI. Q. **When mentally retarded individuals marry, can their offspring be mentally retarded?**

A. In a few rare hereditary disorders, yes, but most children are born normal.

VII. Q. **What can be done to provide broader knowledge in sex education for retarded children?**

A. Sex education can be carried out as with normals but in simpler terms. If one talks about protection, you should spend your energy with real issues demanding your protection such as teaching the child to watch out for trucks, other dangers. Remember with the mentally retarded the understanding of sex etc., comes later when his maturation is more advanced. It is best to think in terms of how you would explain it to say, a five or six year old if the child is 12 with an IQ of 50. Sexual instincts of the mentally retarded are similar to that of the normals but their understanding is different.

VIII. Q. **Should a retarded adolescent marry? Can she and should she have children?**

A. The question of marriage for a retarded person depends on that person's ability to take care of himself, provide for the wife or husband and take care of the child. Most retarded persons are capable of having children but vary considerably in

their ability to care for the offspring. A noted psychiatrist suggested criteria in terms of independence of behavior (social, emotional) and approximately eight years mental age and that the prospective parents do not have a diagnosed heritable condition or where the likelihood of abnormal birth is high. In all instances where this question is of concern to particular parents, the family physician and, or, appropriate regional diagnostic and counseling center should be contacted.

IX. Q. **My ten year old boy masturbates even though I threaten him with punishment of various sorts. What can I do to help him?**

A. In the first place you may need to look at your own attitude, your fears and concerns regarding masturbation. It is not an abnormal behavior nor damaging to the child's growth. You may determine if your own attentions and threats to the child are actually reinforcing his behavior, that is achieving a certain satisfaction from your attentions. You may wish to find out when and under what circumstances he masturbates and try to avoid those situations. You may check with your family physician to assure that there are no organic causes, irritation of the genitals, etc. Also, it may be advisable to check the fit of his clothing. You may try ignoring the behavior and rewarding your child when he is not masturbating. The same principals may apply to your retarded child as well as to your normal child.

X. Q. **How should tantrums in a retarded child treated?**

A. Tantrums seem to have something in common with all children. They may be regarded as something they have learned to do and from which they derive certain satisfaction. Many times we as parents are unaware that the very manner in which we try to correct the behavior, serves as a reinforcement to continue that behavior. Here again, treatment should consist of:

a) Ignoring the behavior if at all possible.
b) Avoiding situations (if possible) that provoked this behavior.
c) Providing praise for the child for his good behavior or non-tantrum behavior.
d) Consulting your family physician to assure that organic problems are not the main cause.
e) Provide other satisfying outlets for your child's energies.

Chapter 6

IMPROVING COMMUNICATION

Parents of retarded children generally consider the ability to communicate, to express one's self and to understand speech to be of prime importance in the development of their child. We live in a world in which we are constantly bombarded by oral language, and most frequently the image one has of the retarded is influenced by the quality and appropriateness of his oral language. Training school staff are most cognizant of the importance of this need, and attempt through varying methods and techniques to expose the child to a continuing barrage of verbal language, with opportunities for the child to respond. Parents of retarded children are often advised to follow a similar approach at home, toward stimulating the child in the development and use of oral language.

Many speech disorders in retarded children are related to sensory system disorders. We know, for example, that the incidence of hearing disorders in the retarded is much greater than in normal children. The inability to concentrate and to listen is also greater in these children. Many retarded children have difficulty "dialing out" extraneous sounds or static, and are frequently unable to separate the appropriate input sounds. Further, these children often have poor muscle control making the pronunciation of certain sounds awkward ("s," "th," "x," etc.). The incidence of neurological impairment, resulting in speech disorders, is also far greater among the retarded than in the normal child.

Communication must precede speech. Communication is not restricted to receptive and expressive speech alone, but includes eye contact, gestures, and other means of making wants known. Merely having a child parrot speech is not as effective as communication, per se. Once a communication pattern has been established, the oral aspect can follow. Following are some of the most common questions asked by parents of the retarded:

I. Q. **Why are speech problems so common among retarded children?**

A. As was mentioned above, there are many factors, more common among retarded children, which contribute to speech disorders. Most important among these is the fact, the overall development of the young retarded child is delayed, so that the speech development, as well as most other areas of growth, comes more slowly. Of importance also, is the problem of shutting out external stimuli, being easily distracted by the slightest noise or stimulus. The problem of "tuning in" the proper stimulus from the myriad of stimuli our culture imposes on us becomes a major factor in the organization of speech. Neurological impairment, (brain damage) contributes to this inability to "dial out" distracting sounds, and also makes it difficult for the child to discriminate as well as to produce certain sounds or letters. Generally, the retarded child tends to make the same mistakes in the input as in the output of speech – viz., they have trouble producing the same sounds that they have difficulty in receiving.

II. Q. **How can parents better observe communication in their children?**

A. Look for patterns of behavior in your child. Ask yourself such questions as, what time of the day does he do much of his talking? How does he let us know when he is hungry? What gains are there for the youngster if he does not speak? Do we occasionally respond to him for not speaking when we could as easily respond to him **only** if he speaks? Does he speak at school and not at home, or vice versa? It is well to talk with the child's teacher regarding his communication abilities at school, and to expect similar patterns in both the home and the school.

III. Q. **Where can I go for help for my retarded child's speech?**

A. Unfortunately, there are relatively few local agencies which are equipped to help retarded children with speech difficulties. Waiting lists are long, and not too many clinics are staffed for this purpose. Perhaps the easiest starting place is with the speech therapist in the local school. The speech therapist for the special class children is familiar with your child's particular problems, and would be in a position to know whether the child could profit from special help, and who might be in a position to offer special suggestions.

IV. Q. **What special techniques might the parent use to help his retarded child's speech?**

A. The techniques would be largely the same as those used with the normal child, as long as the

parent remembers that progress will take longer. The remedial help should be concrete, specific, and functional, rather than general or philosophical. For example, we would help the child with practical words he needs, rather than offering general advice which would apply to all speech.

The all-important rule is that we encourage communication, itself. We encourage a child's communication by **listening** to the child. What a child is saying is far more important then how he is saying it. By our effective listening to the child we are also training **him** to listen as well as to communicate.

The gap between one word and two-word phrases is enormous. After the child has learned to identify objects, people, etc., with one word, we can now begin gradually to use two words together. The use of the second word is generally descriptive or active (Daddy's car, drink water, etc.). Two words represent the beginning of sentences.

A good example of adult speech is important, but not nearly so much as being one who **communicates** with the child in areas other than speech. Too often, we try to correct or remediate the child's faulty speech, rather than encouraging the child's verbal or gestural communication.

V. Q. **Does the parent need special equipment to help his child?**

A. Again, the speech therapist at your school would be in the best position to recommend special equipment which might help your child's special situation. Some families have a tape recorder, which is a valuable device. It gives the child a chance to hear himself as he really is, and to hear others as a model. The child who is unable or unwilling to listen to people will often listen to a mechanical device such as a radio, television, telephone, tape recorder, etc. All children learn best those things they have discovered for themselves, rather than that which they have been told. Children get pleasure and instruction from merely babbling or cooing into a tape recorder and playing it back. The purpose of the tape recorder should be recreational rather than instructional, as far as the child is concerned.

VI. Q. **Just how do we teach our child to listen?**

A. It is important that we as parents do not simply "talk too much" to the child to the extent that he dials us out. We might also need to develop certain means of attracting our child's attention which are unique to the child. This may be unusual or distinctive, according to the particular method that attracts the child. After all, this is the technique of advertising.

We should, whenever possible, combine the senses, linking the visual or tactual with the auditory. Define or describe something the child sees, hears, or feels.

In speech, as in all areas, success begets success. Regardless of his level of speech, the child should be made to feel that he is being understood and is being listened to. To learn to listen, the child needs the model of a good listener in his parents. The child who is made to feel successful in his speech rarely avoids speaking, and is far more likely to improve, than the child who feels he has no audience, or worse still, is frequently corrected when he makes errors.

VII. Q. **How can I help my child's stuttering?**

A. Stuttering is more common in the retarded than in the normal child. Though it is often increased by neurological difficulties, it is caused more by an attitude on the part of the child than anything else. One of the best things a parent can do for his child's stuttering is to simply not focus attention on it. Stuttering, as most other minor emotional manifestations, is increased when attention is brought to it. The parent should be a good listener, provide the child with a good speech model, reward non-stuttering speech and assure the child that he is understood. Generally, the stuttering may gradually disappear. If it does not, the parent examines the causes of nervous tension in the child, attempting to examine and treat the causes, rather than the cure for the stuttering. Stuttering is not nearly as bad as the child not wishing to communicate because of concern over his speech.

Chapter 7

RECREATION

It has been said that play is the work of children; and so it may be, when we observe children in play, it seems a very serious occupation. One of the most fascinating aspects of play is that it provides so much in the way of psychological development for the growing child. Play is the vehicle through which the child achieves much of later values and behavior patterns. Play, therefore, serves an important role in the all around development of the child. It is his method of growing in those areas in which he is ready to develop, i.e., physical, social, mental and emotional growth.

The better control the retarded child has over his own body, the more adequate and confident he can become. Through play he can develop his large and small muscles. The only way a child can learn to control his muscles is by using them. A child will not learn to walk until he is given the opportunity to try; he will not learn to handle a crayon unless he has experience with crayons, etc.

The retarded child's early attempts at learning motor skills will be awkward and sometimes unsuccessful. Repeated experiences in using his muscles, both large and small, give him opportunities to refine his control and use of these muscles. Play is the natural method of gaining these experiences and learning such control. It will usually be a longer time before the retarded child will be able to participate in play with other children. Most of his early play will be done alone. Parents are usually the first playmates of the retarded child. The parents can help him learn to share his toys with them and encourage the sharing of ideas.

Through play the language development of the retarded child can also be fostered. Many opportunities present themselves for teaching the youngster names of objects, people and toys. Later on, one can use words to review and clarify experiences he has had and still later to help him express himself.

An understanding of the physical growth patterns of young children and their socially acceptable play interests is basic to planning a program of recreation for mentally retarded children. As many children need a long period of time to grow from large to small muscle activities, a wide variety of materials are needed to hold interest and to reinforce each small gain in motor control. The same basic principles for a good physical recreation program for normal children apply to a program for retarded children. Activities should be stimulating, socially constructive and esthetically designed. Care should be taken that "free play" does not become an unorganized, overly permissive opportunity. Free play is valuable in learning to share, but requires structuring and careful supervision; it can be the most difficult supervising that a parent or teacher may undertake. It is usually quite misunderstood and therefore loses much of its value. Activities and recreation should be directed towards some purposeful behavior, keeping in mind the child's developmental status and expected progress.

Coordination, rhythm, self-control and self-evaluation are basic components to growth in movement, skill development and general body use. Children can be taught relaxation, by showing them how to tighten and relax their muscles. Retarded children are usually more on the passive side and require specific training in this area. Impulse control can also be taught by encouraging the child to move as slowly as he can by such commands as: stand up slowly, walk slowly, etc., then ask the child to do this on command from a slow to a very rapid movement that can be turned off and on by request in a game like approach.

Success brings in more energy or motivation towards problem solving, and can result in greater effort by the child. The total body should be thought of as a learning channel. Children can be taught to move about in various geometric designs on the ground by skipping, running, walking, etc. Such body movement entails some of the following areas: impulse control; pattern recognitions such as done with pencil and paper materials; letter recognition and later, tranference to paper and pencil shapes and designs; acting out ability to remember things in a series such as spelling, giving commands and so on.

There are many such benefits that can be acquired through play and recreation experiences which will aid the retarded child in better coping with everyday life situation. Children can be taught to work off frustrations and anger through active play, as well as improving their general muscle tone and coordination through activities.

Following are some questions asked by parents:

I. Q. **My child is very lonely, he has no close friends. How can I get him involved?**

A. First try to get him some friends on the block or neighborhood you live in. If there is no one appropriate there, get together with parents of other retarded children and plan some activities together. You may wish to make this a project through the school your youngster attends or the parents' association you belong to. There are other groups that may also be of help to you through some of their special programs such as the Boy Scouts, Woodcraft Rangers, YMCA, etc.

II. Q. **Are playground programs available for the mentally retarded?**

A. Yes, they are available for all children. The County Parks and Recreation Department may be able to offer special assistance for some of the retarded children through their extensive programs. You should make your needs known to them if there is no such program available at the time. The initial contact should be with your local playground director to discuss your individual child's needs — his assets, limitations, etc.

III. Q. **How can I best prepare and attempt to provide for my child's social needs?**

A. Parent associations for the mentally retarded have proven to be of great value in dealing with such concerns. Your local school principal or special class teacher, as well as the special staff working with the retarded in local school districts or county superintendent of schools office can be of help to you and your child.

IV. Q. **What kinds of activities do the retarded enjoy?**

A. Like normal children, they enjoy most sports in keeping with their ability. Baseball, volleyball, running and jumping activities as well as swimming are enjoyed by most. Retarded children of course, are usually less well coordinated than normal children and will thus require greater time and patience with some sports. Other sports demanding higher coordination may be postponed for later.

V. Q. **Are there summer programs for the mentally retarded?**

A. Yes, some of your local public schools as well as churches and private groups often offer such programs. If you are not sure as to what is available in your area, it is a good idea to contact the Regional Center for the Mentally Retarded and inquire of the counselor serving your geographical area what may be available. (See appendix A describing Regional Center). The recent Olympic Games for the Mentally Retarded sponsored by the Kennedy Foundation has been most successful in focusing attention on importance of physical development in the total growth of the retarded. At the same time, parent groups also sponsor competitive activities in bowling, swimming, etc.

VI. Q. **Our neighbors do not want their children to play with our retarded youngster. They fear that they will pick up bad habits, be injured, or the like. What should I do?**

A. The parents should first examine the neighborhood structure, and should determine whether the neighbor's concerns are justified. Is the child being properly supervised, clothed, etc? The next logical step is to familiarize yourself with the concerned neighbors. The more they are invited into your home for visits, coffee, or dinner, the more they can see the reality of the picture, and can identify with their part of its solution. Rarely is there this concern when the parents have good relations with the neighbors. The parents might even ask the neighbors' advice on handling the problem, once rapport has been established. Such concerns as "danger," "picking up bad habits," etc., are usually the result of lack of understanding as well as poor neighborhood relations. The parents of the retarded may appreciate the fact that acceptance of any handicap is furthered by knowledge and understanding of the handicap.

Chapter 8

VOCATIONAL TRAINING FOR THE MENTALLY RETARDED

Slightly over a decade ago, there were very few vocational training facilities for the trainable retarded. Those few that did exist, were found in the larger areas and operated mostly by parents' groups. With the considerable increase in numbers of trainable retarded found in California's public schools, a concern was raised regarding those pupils who reached maximum age and had to be terminated from further attendance. Most of these pupils who reached age 18, left school only to return to their homes and gradually lose the skills learned at school and become increasingly dependent on their parents. Recognizing this problem, the California Legislature extended school attendance for the Trainable retarded as follows:

a. Permissive attendance starting at age five.
b. Mandatory attendance, age six to 18. (Effective Nov. 1969).
c. Permissive attendance, age 18-21. The pupil who reaches 18 must be assigned to a sheltered workshop for several hours a day and attend special class for a minimum of three hours per day. If a workshop assignment is not available or where the pupil is found incapable of profiting from such an experience, he is terminated from school attendance. A pupil may continue to attend the workshop and school until he reaches 21 and is then terminated at the end of the school year and hopefully he would continue at the workshop.

School districts and County school offices are permitted to enter into contracts with directors of sheltered workshops for the training of pupils. There needs to be a mutual agreement that the pupil will benefit from additional schooling and from his experiences at the workshop. The latter provides the pupil with adequate supervision, a variety of work training activities and an evaluation of the pupil's performances. Continuation of the pupil's attendance at the workshop after 21 years is contingent on available space and minimum productive ability of the trainee as well as getting along with others.

Public school classes for the trainable retarded are focusing on prevocational activities approximating those of the sheltered workshop in order to facilitate the transition of pupils to real work programs.

Most of the sheltered workshops pay the student trainees a minimum compensation ranging from 5-10¢ per hour to almost minimum wage rates. Whatever the pay is, it serves as an excellent motivating factor for the student and often leads to unexpected improvement in his performance and behavior. Much of the work done by the trainees includes counting and small packaging, assorting by color, size, shape; stapling, labeling, assembling, separating, etc. A contract between the school and workshop for the training of its students requires the workshop to provide a variety of work activities and evaluation of student performance by the director. Both the school and workshop director work closely to assess the progress of the pupil in class and in the workshop. Accordingly recommendations are made to help the pupil improve his performance and personal social behavior. In a number of instances the Vocational Rehabilitation Agency helps a trainable youth who is capable of more skilled work to obtain special placement in industry. The public is becoming more aware of the need for some type of employment for the retarded. The combined efforts of parent groups, schools, rehabilitation and social welfare agencies may serve to hasten the time when the state, local and federal governments as well as industry, will make possible the establishment and subsidy of adequate number of workshops with trained directors to serve the increasing employment needs of the retarded.

Following are some of the commonly asked questions:

I. Q. **How can we as parents prepare our child for vocational success?**

A. Training for such a goal may well start in early childhood — (especially for the trainable retarded) the person with positive self attitudes is more likely to achieve a successful community placement. Such positive attitudes are developmental and learned from infancy. Parents can provide their child with tasks of varying degrees of difficulty as well as challenge (within their levels) and thus with proper guidance, encourage their child to stretch their minds in completing the task.

Other ingredients tending towards achieving vocational success are:

a) Proper self-care (body, dress, appearance).
b) Completion of tasks — perseverence.
c) Understanding and following directions.

d) Working towards a goal – money for what it can buy, other rewards satisfying to the child.
e) Parents expecting child to perform task as well as he can and letting child know this.

II. Q. **What opportunities are there for those retarded who show work abilities beyond those found in a sheltered workshop?**

A. There are generally three levels of performance for trainable retardates:

1. Transitional level – The retardate shows ability beyond the level of the rest of the group in the workshop. In this instance efforts are made by the workshop director, school, parent group and vocational rehabilitation agency to secure specialized placement in a shop where the youth's skills can be utilized to his advantage. A small shop with easily available supervision is helpful. Sometimes, parents themselves have shops where they can use this type of help.

2. Terminal level placement – The worker finds the sheltered workshop compatible with his level of performance and remains there on a partially productive level, earning several dollars or more a week in accordance with the quality and quantity of his production. Here again, the basic values of the workshop lie in the opportunity for the individual to come daily to work, earn money, feel comfortable with other workers, and acquire a sense of worth and personal dignity.

3. Activity level placement – There are a number of trainable retardates who for some reason or another are unable to function profitably in the average sheltered workshop (poor hand-eye coordination, lack of sustained attention to the task, inability to understand and follow directions, difficult personal social behavior, etc.). Most of the sheltered workshops depend on certain production levels to keep them in existence and thus cannot maintain workers of the type mentioned above.

Where level of production is not essential to existence, some few workshops have included a section for such activity level workers, where the purpose is to provide a sort of occupational therapy where the worker can attend daily, and benefit from the personal-social, recreational experiences available in such a setting. It is expected that the activity level center would need to be subsidized by tuition fees, donations or other funds. There is much need for additional centers of this type as well as for regular sheltered workshops.

III. Q. **How are workshops funded?**

A. A parent group for example, may incorporate and raise a certain amount of money and apply to Vocational Rehabilitation Service for expert consultation as well as for financial support if the planned workshop meets with the Agency's requirements. The workshop director with his board of directors must establish a budget with some of the funds coming from work contracts with industry, and from work evaluations of clients referred by Vocational Rehabilitation Agency and from contracts with school districts and, or, County Schools Offices for the training of pupils 18-21 years.

IV. Q. **How much is paid to workshops for training pupils?**

A. In California, public schools sending trainable youth to workshops between ages 18-21 average contracts as follows:

First school year – to $500 per youth
Second school year – to $400 per youth
Third school year – to $300 per youth

V: Q. **What kinds of work can our children do when they grow up, in addition to sheltered workshops?**

A. There is a wide range of abilities among the trainable retarded. Depending on the geographical area one lives, trainable level youths may be capable of working at various jobs as follows:

1. ranch or farm
2. restaurants – bus boy, dishwashing
3. golf courses – caddy, minor custodial work
4. cannery – assembly line jobs
5. gardening – as helpers to gardeners
6. packaging – plants – furniture assembly, toy assembly, shoe assembly
7. office helpers
8. picture framemaker helper
9. Clay – pottery factory
10. Laundry plants

It is hoped that the skilled training officer of the Vocational Rehabilitation Agency might seek out additional job situations in industry where trainable youths might well succeed in.

VI. Q. **What is being done to fill in the gap of time between the child's return home from school in the early afternoon and the remainder of the day?**

A. This is an important question. Many parents are prevented or limited in pursuing a full day's out of home activities, employment, volunteer work, personal activities, etc. because their child returns home early and supervision of the child is necessary. Baby sitters may be difficult to obtain and costs may be beyond parents' means. Recognizing a need for a type of center where their children and youth may attend for the intervening hours, a group of parents are formally requesting appropriate agencies for assistance in the construction and maintenance of such facilities. The Mental Retardation Services Board of L. A. County has provided for a representation of parent groups interested in developing a program.

VII. Q. **What is being done to find new jobs for the retarded – outside of sheltered workshops?**

A. Dr. Salvatore De Michael, Assistant Commissioner for the Vocational Rehabilitation Administration in New York State, reports, 'Under a federal grant, the National Association for Retarded Children has opened up thousands of job opportunities with such big companies as Howard Johnson, Hot Shoppes, Woolworths, Sears-Roebuck. The U. S. Bureau of Apprenticeship and Training contracted with National Institute of Launderers and now can't keep up with job market demand'. Service occupations are 20% higher now than in 1960."

It is always important for the retarded to receive a good education, prevocational training, assistance in job placement and follow up and to provide such persons equal opportuinties for upgrading in employment levels as with other persons. One might feel that a person with average ability or above would be capable and want to work at a higher level job than one with lesser ability.

A final word here – Industry can be helpful to us in the schools by forecasting the types of jobs more likely to be available 5-10 years from now so that schools might also retool and redirect prevocational emphasis in training the retarded.

Chapter 9

LEGAL AND SOCIAL SECURITY PROVISIONS

As a rule of thumb, it might be said that the laws which apply to the normal also apply to the mentally retarded. There are certain provisions of the Social Security Act of which the parents of the retarded need to be aware. There is Aid to the Totally Disabled (ATD), for example, which may apply to many retarded youngsters at age 18. ATD, which is administered by local and county office public assistance, offers financial assistance. There are also certain additional Social Security benefits available to the retarded. These are secured through the local Social Security Administration Offices.

The fact that a child is retarded, however does not necessarily mean that he is automatically "disabled" and eligible for these benefits. The degree of retardation must be such that the individual is considered unable to provide for himself economically.

Aid to the Totally Disabled is available for the eligible retardate over age 18. This is an assistance program, eligibility for which is dependent upon need. Social Security benefits, on the other hand, are derived from the contributions of the parents, and are not dependent upon need.

The questions of wills, trusts, liability, etc., generally require the assistance of an attorney.

Following are some common, practical questions often asked by parents:

I. Q. **Am I liable for the wrong doing (torts) of my retarded child?**

A. As with the normal child, the parent must assume liability for the wrongful acts of a retarded child. The fact that the child may not be considered responsible for these acts does not lessen the parents' liability. A young retarded adult of 21 is, himself legally responsible for his own acts, though his condition may certainly be used in his defense. In several test cases, however, the parents of a 21-year-old were held liable, because they were aware of the youth's behavior, and had not taken precautions to prevent the act.

II. Q. **How should I leave money for my child's future?**

A. In the case of the retarded, as well as with the normal, it is most hazardous to assume that property will be equitably distributed unless adequate provisions have been made. Legal counsel is usually advisable.

A will is an instrument that directly disposes of property to the designated beneficiary upon the death of the maker of the will. A trust is a method of transferring property either during life (inter vivos) or upon the death of the maker.

A trust may be set up in any way the person making the trust (trustor) wishes. A trust document may include such things as distribution and investment of property. Retardates are generally incapable of handling their financial affairs; therefore, it is desirable that provisions be made for this purpose. A trust is the usual instrument for doing this.

Money for a retarded child should not be left directly (willed) to the child, but preferably should be in a trust situation, with a trustee, legally appointed, who will handle the financial affairs for the benefit of the retarded beneficiary. Trusts contain safeguards to protect the interests of the retardate.

Guardianship provisions should be previously discussed with the prospective guardians.

III. Q. **Must a retarded child pay inheritance taxes?**

A. Yes, inheritance taxes cannot be avoided. Proper estate planning, however, can simplify future problems involving the inheritance of property.

With regard to leaving money to an institution on behalf of a resident (present or future) child, the parents should be sure to consult an attorney to best determine the disposition of property to an institution. A state institution has the right to charge the estate of any individual who is receiving direct services from the institution. No state institution will release a child if private funds become unavailable. The private institution is another matter. The fees, usually higher than a state institution, are generally paid in advance. An attorney, legal advisor, or regional center services counselor should be consulted in making financial arrangements for future institutionalization.

IV. Q. **Are all retarded children eligible for Social Security benefits?**

A. Social Security, unlike ATD, is made up of actual savings through earnings of the parents, and are not dependent upon the present financial condition of the family. Therefore, the retardate is eligible to receive benefits in keeping with the parents' earnings under Social Security.

Parents who are or who have been employed by organizations not covered by Social Security (post office, railroads, military, state or government services, etc.) should check with their local Social Security Administration.

Generally, the retarded child who is considered disabled may become eligible for Social Security benefits (for life) when the working parent becomes eligible for retirement or disability benefits, or should die. The age of the young retardate does not matter. The retardate may be very young, or could even be 50 or 60. The key factor is that the retardate's disability occurred before he reached age 18.

The amount of these benefits is largely based on the earnings of the parents. In the event of the father's retirement, disability, or death, the child's mother may also be eligible for monthly payments as long as the child is in her care, regardless of the age of the mother or child. (Benefits to the child who is **not** disabled will stop at age 18, or may continue until age 22 if he is attending school full time). Thus, the life-long benefits to the retardate becomes a significant factor.

V. Q. **How does one make application for Social Security benefits?**

A. If the child is already receiving payments because of a parent's retirement, etc., the Social Security office should be informed about the child's disability about 3 - 6 months before his 18th birthday. If he is found to be disabled, the benefits will then continue. It is important that this application be made. Many parents fail to realize that unless the Social Security office is notified, the payments will discontinue at age 18. Back payments can be made only up to 12 months, if application is made after the child has become eligible. For a new application, for those not already receiving benefits, a similar procedure should be followed. The use of this money for the benefit of the child is supervised by the Social Security Administration.

All Social Security offices are easily located through the telephone directory under "Social Security Administration." If necessary, a representative of the Social Security office can come to the person's home (or institution) to help in completing the application.

VI. Q. **Who receives the Social Security checks?**

A. If the retarded child is under 18 (or is over 18 but unable to handle his own money), the Social Security Administration makes the benefit checks payable to the parents or relatives with whom the child is living. Frequently, payments are made on behalf of the child to a legal guardian or representative of an institution or non-profit agency, which has been named to handle the funds.

VII. Q. **If the child is receiving Social Security payments, may he also obtain Aid to Totally Disabled?**

A. Social Security payments, not being affected by the family's financial status, are automatically paid, and are not influenced by ATD or other outside income. Therefore, the child **may** receive both, but the amount of ATD received **will** depend upon the family's economic status. If Social Security payments are not sufficient for the retardate's needs, Aid to Totally Disabled payments may supplement inadequate social security payments.

VIII. Q. **How is the amount of Social Security benefit determined?**

A. Benefits to the disabled child will vary according to the past earnings of the parent. In computing the amount of the benefits, the earnings of the parent are averaged. Those parents who averaged higher incomes (up to $7,800 annually) would receive relatively higher benefits than those who earned less. The money comes directly from the Social Security funds, which have been paid in by the worker and his employer. Social Security was never intended to take the place of the previous income, but to aid the worker in his retirement. The amount of benefits is also based on whether the survivor(s) have lost their support.

Payments are available if either of the working parents is over 62 and retired, or if the parent is disabled or deceased.

Parents of retarded children may wish to consider the financial advantages of early retirement by consulting with their Social Security Administration. The benefits to parents of retarded children are often nearly as great as if they were to delay retirement.

IX. Q. **What steps would I take to promote legislation regarding retarded children?**

A. The local parent group is the best starting place to promote legislation. They have the addresses of the regional and state groups. In addition, you should contact the State Senator and Assemblyman serving your area. Much of the legislation affecting the mentally retarded has been initiated, and promoted by the concerted interest and action of organized parents and professional associations and by the recognition and acceptance of such group efforts by our State legislatures.

Chapter 10

COMMUNITY AND ITS RESPONSIBILITIES

As far as it is possible, community services should be used for the mentally retarded. It is important to the family as well as community that the retarded be included in community programs.

The health and diagnostic needs of the retarded should be met by existing community health centers. Their educational needs should be provided for by the public schools, recreational needs should be provided for by parks and recreation departments of the community; welfare needs by local departments of welfare, etc. Specialized programs as well as personnel may be needed within these community resources in order to provide effective services to the retarded.

Community services to the retarded is based upon the belief that all people in need of service should be provided these services as close to his normal environment as possible. The needs of the retarded should be met in such a way that his family and peer ties should not be disrupted. Although community services should, wherever possible, be provided on the local level, the responsibility for these services should be shared with the state and to a degree with the federal government.

Community efforts for the retarded are not only the responsibility of official state agencies such as the school, hospitals, and welfare organizations but also of parent groups. The participation of individual parent leaders within the professional leadership should be encouraged. As an example the school personnel should be working with parent groups for the retarded.

The effective utilization of community resources at times is a very complex task. The knowledge of the kind of service needed and the findings of the agency which has such service available as well as "knowing the ropes" well enough to avail one's self of such service can be overwhelming for the parents of the retarded. Because of this, many communities have developed a place which serves as a fixed point of referral and information which provides on-going or "life" consultation services to the retarded and his family.

Perhaps the 'major breakthrough' in the care of the retarded has been in the area of community services. Much has yet to be done. Retardation requires a lifetime of community care. These services must be related to the needs of the retarded as he passes through his various life stages. Some communities provide some of the services, however, the entire "spectrum" of community services should be available. In the past few years community services have been examined and the organization of services at the various ages have revealed the existence of gaps in services. Sometimes a retarded child receives no services until he enters school and then after eight or ten years of school he is sent home to remain in a dependent position for the rest of his adult life.

A model for comprehensive life services for the mentally retarded children and adults is presented.* The scope of services needed may appear overwhelming but it should be noted that some of the services needed by the retarded can, with some exceptions be provided for in agencies already existing in many communities. With some modifications existing community agencies can extend their services to the retarded. Others, of course, will require legislative action and implementation.

Social Welfare Services –

- Financial assistance
- Homemaking Services
  - Home economist consultation
  - Mothers' helpers or homemaker service
- Placement Service, including adoption service
- Community Residential Care
  - Short term residential care
  - Foster family care for children and adults
  - Other specialized residential care programs
- Transportation
- Life Counseling for retardates and their families
- Community Organization Work

Educational Services –

- Day Care Centers
- Nursery Schools
- Special Classes for the educable mentally retarded

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*A Mental Retardation Survey of Los Angeles County. A Report of the Joint Agencies Mental Retardation Project. Welfare Planning Council of Los Angeles, California, 1965.

- Primary
- Elementary
- Secondary

Special Classes for the trainable mentally retarded.

- Elementary
- Secondary

Adult Education

- Special programs for the mentally retarded included in regular programs.

Clinical Services –

- Prevention
- Family Planning Clinics
- Prenatal Care Clinics
- Child Health Conferences

Diagnosis

- Casefinding, including Child Health Clinics and population screening.
- Inter-disciplinary Diagnostic Clinics, such as Child Development Clinics.
- Medical, including biochemistry, neurology, ophthalmology, pediatrics, and psychiatry.
- Psychological.
- Social.

Treatment

- Medical therapy.
- Chemical therapy.
- Psychotherapy.
- Medical counseling for retardates and parents.
- Psychological counseling for retardates and parents.
- Casework and groupwork.
- Family Service.
- Nursing Care.

Amelioration

Public Health Nursing Supervision

- Home training.

Health Education

Recreational Services –

- Programs for socially "independent" retardates
- Programs for socially "semi-independent" retardates
- Day camping programs
- Overnight Camping programs

Vocational Habilitation and Employment Services –

- Pre-Vocational training
- Vocational training
- Vocational counseling for retardates and their families
- Work experience programs
- Sheltered Workshop Services
  - Evaluation workshop
  - Training workshops.
  - Continuing employment workshops.
  - Occupational day care centers.
- Employment Placement Service
- On-the-job Supervision

Legal Services –

- Legal Assistance
  - Criminal.
  - Civil.
- Conservatorship
- Guardianship

Following are some of the questions parents ask regarding community services:

I. Q. **How does a parent find out if a needed service is available in the community?**

A. Many communities maintain a welfare information service. This is usually maintained by the local Community Chest agency. Your request for information to the Welfare Information Service will result in a professional social worker referring you to the most appropriate agency for your problem. You will find Welfare Information Service listed in the yellow pages of the telephone book under Social Service and Welfare. Some agencies are listed in the appendix.

II. Q. **What if a service is not present in the community?**

A. It is most unlikely that existing agencies cannot provide some portion of needed services. Unfortunately, some of these agencies have not pictured themselves as offering their services to the retarded. The presentation of your need and those of others should be made. This can be done as an individual

as well as with groups of parents with similar needs. In some cases where the service is not part of the repertoire of existing agencies, parent groups can set up demonstration projects or even continue operation of needed services. The eventual goal in most cases should be the absorption of parent projects by existing agencies.

III. Q. **What are some ways we can inform the public about Mental Retardation?**

A. There are various means to communicate and inform people about Mental Retardation.

1. Radio, T.V. presentations
2. Newspaper articles, columns, magazine articles, college courses
3. Public forums, lecture series, benefit affairs
4. Exhibits of materials produced by the retarded
5. Competitive sports among the retarded and publicized
6. Becoming individually knowledgeable and answering your neighbor's questions.

APPENDIX

Los Angeles County public and private agencies and associations serving the mentally retarded have increased significantly in number and in services available. An effort has been made to gather information about these sources for service in the hope they may be of help to the retarded child and his family as well as to school personnel and other agencies serving the retarded. The writers make no claim to a complete listing of such agencies nor does inclusion of the private training and workshop facilities imply endorsement. Central sources have been listed in most cases where the reader may call to inquire about branch facilities and services that may be available closer to their home.

APPENDIX A

SOME AGENCIES SERVING THE RETARDED AND HIS FAMILY

1. Los Angeles County Superintendent of Schools Office,
   155 W. Washington Boulevard,
   Los Angeles, Calif. 90015
   Tel: 748-6561 Ext. 374.

   For information regarding public school classes for the various types of exceptional children served by the school districts and county office.

2. Regional Center for the Mentally Retarded,
   Children's Hospital,
   4650 Sunset Blvd.,
   Los Angeles, Calif.
   Tel: 663-3341.

   Serves as a focal point for information and services for families having retarded children. Services not denied if unable to pay.

3. Mental Retardation Services Board,
   1313 W. 8th St.,
   Los Angeles, Calif. 90017
   Tel: 483-9612.

   A board composed of representatives of public agencies serving the mentally retarded in Los Angeles County. With its director, attempts for planning and coordinating such services. May also provide information and consultation to parent groups as well as other public and private agencies.

4. Social Security Administration,
   Central Office,
   419 So. Hill St.,
   Los Angeles, Calif.
   Tel: 688-3716.
   For information and assistance regarding benefits to families of the retarded as well as to the retarded person himself.

5. Los Angeles County Dept. of Public Services, (DPSS)
   4900 Triggs Ave.,
   Los Angeles, Calif.
   Tel: 268-8281.

   Headquarters for information for aid to dependent and totally disabled.

6. Vocational Rehabilitation Division of the State Dept. of Rehabilitation,
   District Office,
   107 So. Broadway,
   Los Angeles, Calif.
   Tel: 620-4370.

   Provides complete assessment, training and placement of the retarded person eligible for its services. Also offers information and consultation to parent groups planning to establish a sheltered workshop.

7. Los Angeles County Parks and Recreation Dept.
   Special Services Section,
   155 W. Washington Blvd.,
   Los Angeles, Calif. 90015
   Tel: 749-6911.

   Provides year round recreational programs in various sections of the county to mentally retarded children and adolescents. Works closely with parent groups. Some other recreation departments within the county also provide special service programs for the retarded.

8. Economic and Youth Opportunity Agencies of Greater Los Angeles,
   314 W. 6th St.,
   Los Angeles, Calif. 90014
   Tel: 629-5511.

   A coordinating agency for information regarding programs of Head Start, Neighborhood Youth Corps, Jobs Corps, Vista and others. Also for information on location of Head Start centers serving mentally retarded preschool age children.

APPENDIX B

ORGANIZATIONS OF PARENTS OF MENTALLY RETARDED CHILDREN IN LOS ANGELES COUNTY

1. Exceptional Children's Foundation,
   2225 W. Adams Blvd.,
   Los Angeles, Calif.
   Tel: 731-6366.

   Provides psychological assessment and counseling center, training classes for preschool and school age pupils, in nine locations with 15 classes. Workshops listed in other section.

2. Antelope Valley Association for Retarded Children,
   1734 E. Ave., H-8,
   Lancaster, Calif.
   Tel: 942-8195 (area code 805)

   Provides training classes for retarded children not eligible for public school. Called Desert Haven Training Center at same site.

3. San Gabriel Valley Assn. for Retarded Children,
   529 So. 2nd St.,
   Suite C,
   Covina, Calif. 91722
   Tel: 332-9517.

   Training classes and activity center.

4. Ontario Pomona Assn. for Retarded Children,
   91630 Monte Vista,
   Montclair, Calif.
   Tel: (714) 986-4369

   Provides training classes and workshop for the retarded.

5. Villa Esperanza,
   2116 E. Villa,
   Pasadena, Calif.
   Tel: 449-2919.

   Provides training classes and a child development center for infants diagnosed or suspected of mental retardation. Maintains a workshop.

6. Intercommunity Exceptional Children's Home,
   2666 Grand Ave.,
   Long Beach, Calif. 90815
   Tel: 426-1721.

   Residential and school facilities for the retarded. Ages served, 3 to 60 yrs.

7. Mid Cities Assn. for Retarded Children,
   114 E. Alondra Blvd.,
   Compton, Calif. 90220
   Tel: 638-4639.

   Provides a sheltered workshop for boys 16 yrs. and over.

8. Exceptional Children's Opportunity School,
   12204 So. San Pedro St.,
   Los Angeles, Calif.
   Tel: 756-2566.

   For residential and day care of mentally retarded. Training classes available.

9. Glendale Assn. for Retarded Children,
   P. O. Box 467,
   Glendale, Calif.
   Tel: 244-9412.

   Classes for children ages 3-16 yrs. Workshop for those 16 years and over.

10. Burbank Retarded Children's Center,
    3300 W. Olive St.,
    Burbank, Calif.
    Tel: 843-4907.

    Training classes.

11. San Fernando Valley Assn. for Retarded Children (New Horizons Center),
    15725 Parthenia,
    Sepulveda, Calif.
    Tel: 894-9953.

    Training classes.

12. Los Angeles Retarded Children's Foundation,
    3052½ E. 4th St.,
    Los Angeles, Calif.
    Tel: 268-9477.

SHELTERED WORKSHOP FACILITIES

13. Foothill Industries Civitan Workshop for the Handicapped,
    130 No. Fair Oaks Ave.,
    Pasadena, Calif.
    Tel: 449-0218.

14. Community Rehabilitation Training Center,
1030 E. Cypress St.,
West Covina, Calif.
Tel: 339-1618.

15. Lincoln Training Center and Rehabilitation Workshop,
2527 Lee St.,
So. El Monte, Calif. 91733
Tel: 442-0621.

16. San Gabriel Valley Training Center and Workshop for the Handicapped,
10901 E. Bryant Ave.,
El Monte, Calif. 91731
Tel: 448-5312.

17. Nova Opportunity Center Workshop,
506 No. Victory Blvd.,
Burbank, Calif.
Tel: 846-5620.

18. PAR Workshop Central,
1726 W. Pico Blvd.,
Los Angeles, Calif. 90015
Tel: 387-4222.

19. PAR Workshop, Eastside,
11990 Rivera Rd.,
Santa Fe Springs, Calif. 90670
Tel: 693-8629.

20. New Horizons Sheltered Workshop,
19731 Bahama St.,
Northridge, Calif.
Tel: 341-7711.

21. LARC Ranch
Resident Home For The Mentally Retarded,
29890 Bouquet Canyon Road,
Saugus, California
Tel. (805) 252-8636

22. Elkhorn Ranch (ECF)
Resident Home for Mentally Retarded,
10067 Escondido Road,
Saugus, California
Tel. (805) 947-5404

APPENDIX C

COMPARISON OF DEVELOPMENTAL LANDMARKS FOR NORMAL AND DOWNS SYNDROME CHILDREN*

Partial reproduction of the results of a study of normal and Downs Syndrome children is intended to provide the reader with a broader knowledge and perspective regarding age range expectancies in development of these children. The reader should be cautioned that the ages shown for each development are average and may not apply to any particular child. Where the particular item (smiling, walking, etc.) has not been achieved by the Downs Syndrome child much beyond the expected age, the parent may wish to consult with the family physician or clinic. It is interesting to note that in early areas of development, one fourth of the Downs Syndrome children developed as well as the average normal child. However, achievement of an item by 90% or more of the D. S. group was considerably beyond the average age of the normal child. Self feeding, bladder, and bowel control of average Downs Syndrome children was achieved about a year later over average normal children, but here again 25% of the Downs Syndrome group achieved these tasks at the same age as the average normal child!

The reader may well speculate on these differences and similarities and concern themselves with more effective training programs to help lessen the differences where possible, between the two groups.

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*With grateful appreciation to Dr. Jack Share for permission to reproduce in part, the results of a research study he conducted at Children's Hospital, Los Angeles, California.

APPENDIX C

COMPARISON – NORMAL AND DOWNS SYNDROME CHILDREN

ITEM	Normal Child, average age in months. (Gesell scales)	Downs Syndrome Child – average age in months	Downs Syndrome child Achieved by ¼ or 25% of group.	Achieved by 90% of group of Downs Syndrome children
1. Smiles	2	3.6	2	6
2. Holds head erect.	3	5.8	3	10
3. Laughs aloud	4	6.9	4	12
4. Rolls over.	5	8.5	5	13
5. Takes solids well.	7	10.8	7	18
6. Transfers objects in hands.	7	11.4	8	18
7. Sits unsupported for one minute erect.	8	12.7	9	20
8. Crawls and pivots.	8	15.7	11	24
9. Feeds self in part	9	17.2	11	28
10. Pulls self to standing position.	10	18.6	14	30
11. Says Dada or Mama	10	15.4	10	24
12. Cruises at rail of play pen.	12	20.6	15	31
13. Walks with support.	13	22.1	17	33
14. Stands unsupported.	14	24	18	35
15. Walks unsupported.	15	27	21	36
16. Walks upstairs with support.	18	31.2	24	48
17. Obeys simple demands.	18	29.4	22	42
18. Able to seat self in chair.	18	29.8	22	42
19. Walks downstairs with support.	21	32.1	24	48
20. Drinks from cup unassisted.	21	30.1	22	48
21. Word combination. (2 to 3 words.)	21	39.5	30	54
22. Draws or imitates a circle.	24	47.5	36	60
23. Climbs stairs up and down alone.	24	39	36	48
24. Feeds self fully.	24	33.2	24	48
25. Bladder control daytime.	24	34.2	24	48
26. Bowel control (rare accident).	24	35.6	24	54
27. Sentence (3 words).	24	50	46	64
28. Dresses self simple garments.	24	43.8	39	54
29. Dresses self partially (shoes, buttons).	36	49.8	48	60
30. Washes and dries face and hands alone.	42	50.1	46	60
31. Brushes teeth unaided.	48	47.7	42	57

APPENDIX D

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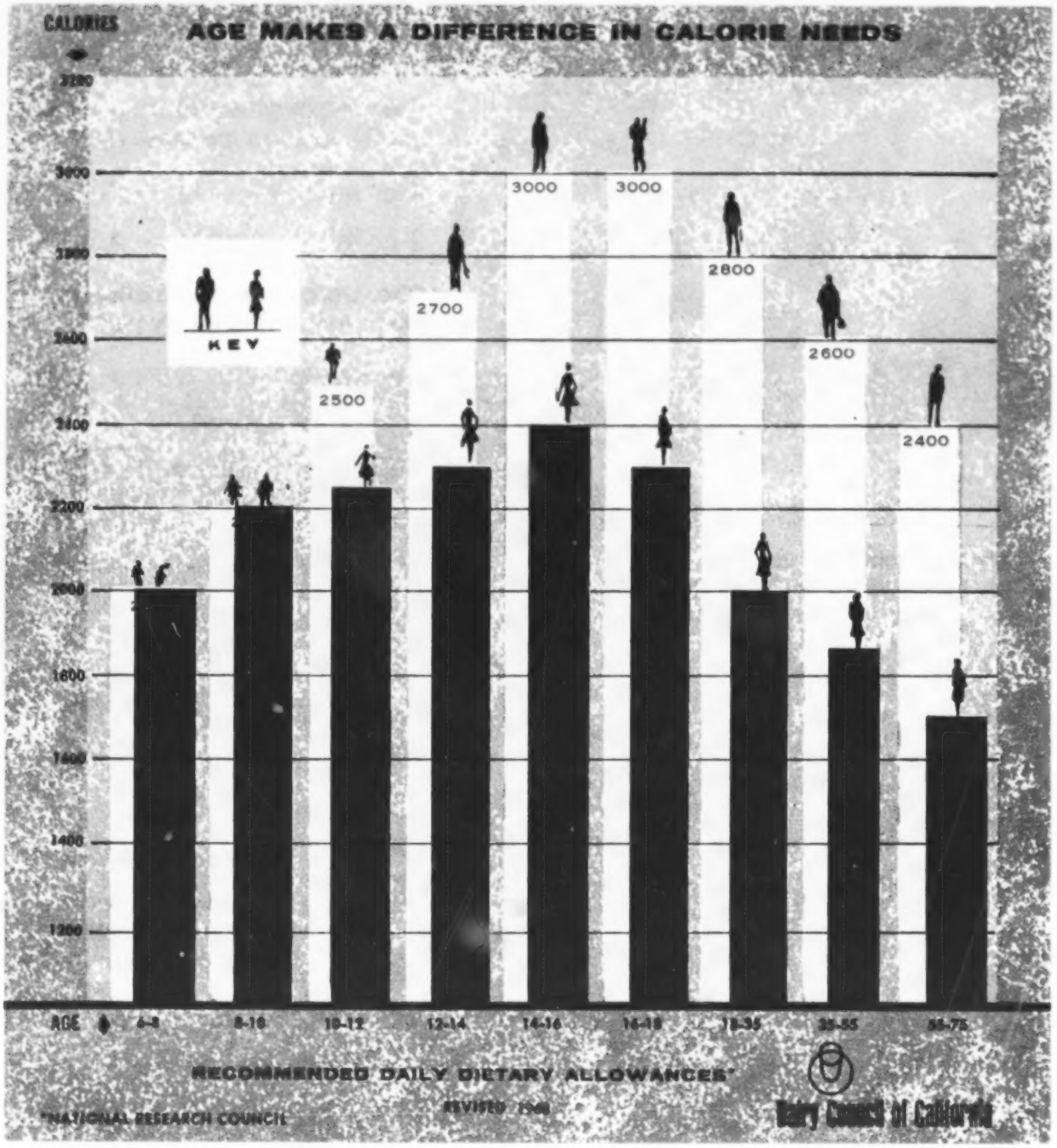
APPENDIX E



The chart and illustration in Appendix E and F have been reproduced with the permission and courtesy of the California Dairy Council and the National Dairy Council.

A Guide to Good Eating

Use Daily:

Milk Group

3 or more glasses milk — Children
smaller glasses for some children under 8

4 or more glasses — Teen-agers

2 or more glasses — Adults

Cheese, ice cream and other milk-made foods can supply part of the milk

Meat Group

2 or more servings

Meats, fish, poultry, eggs, or cheese—with dry beans, peas, nuts as alternates

Vegetables and Fruits

4 or more servings

Include dark green or yellow vegetables; citrus fruit or tomatoes

Breads and Cereals

4 or more servings

Enriched or whole grain
Added milk improves nutritional values

This is the foundation for a good diet. Use more of these and other foods as needed for growth, for activity, and for desirable weight.

The nutritional statements made in this leaflet have been reviewed by the Council on Foods and Nutrition of the American Medical Association and found consistent with current authoritative medical opinion.